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Stories of the success of infants and toddlers speak to the power of Iowa legislative action. In 2007, the Iowa General Assembly invested in the future of Iowa's most vulnerable citizens. That investment has reaped success stories of infants and toddlers with or at-risk for developmental delays who are now learning, growing and reaching their full potential. The first-time state appropriation to Early ACCESS (HSB 289) has enabled service coordinators, dietitians and nurses to use their expertise in partnership with families to help these young Iowans. The following three stories exemplify the many successes resulting from the legislation.

Hailey

Hailey Schnell, 2 $\frac{1}{2}$, greets her many weekly visitors at the door with a smile and a wave. Hailey recognizes her team of service providers since her mom, Tracie, made her a card file with photos to help her learn the faces of those who provide care to her in her home.



Hailey is the daughter of Brian and Tracie Schnell of Graettinger, IA. She was born in Emmetsburg where it was discovered that her oxygen level was low and she was having difficulty breathing. Hailey was flown to Sioux Falls, S.D., where she was diagnosed with coarctation of the aorta of the heart and transferred to Ann Arbor, MI. where she and Tracie remained for four months, enduring four major surgeries, including her first heart surgery. The Schnells then transferred to St. Mary's in Rochester, MN for operations on both her heart and lungs. After eight surgeries in seven months, Tracie and Brian brought Hailey home with a tracheostomy for breathing, a G-tube for feeding and 16 hour-per-day nursing care. Tracie said, "At first we feared we would never be able to bring her home, and then we had such anxiety over what her mental and physical conditions would be like."

Lynn Park, the waiver nurse for Child Health Specialty Clinic [CHSC], contacted the family and a home visit was set up with CHSC's Barb Wilkerson, ARNP and Early ACCESS Service Coordinator, Sally Phelps. Even though Hailey continues to be seen by specialists at the Mayo Clinic, Tracie feels the isolation of having a special needs child in a rural area. CHSC follow-up visits and the Early ACCESS program have helped her coordinate a team of service providers so as a family they feel more confident that Hailey will be able to function in a school setting much like her peers. Hailey receives physical therapy, occupational therapy and speech-language services through Prairie Lakes AEA. In addition to all of these home early intervention visits, Early ACCESS coordinates appointments and follows progress through CAMPS (Children Achieving Maximum Potential Services) at the Spencer Hospital for feeding therapy and additional speech sessions. With this incredible team for Hailey, Tracie says "Early ACCESS offers us hope and encouragement by researching and answering our questions, brainstorming ideas and problem solving, goal setting and being friendly, open and honest." For this they are appreciative and grateful.

The future for Hailey is very bright..."positively wonderful," says Tracie. They are looking forward to getting her tracheostomy removed in the next few months, eating on her own, getting out and being more mobile in the community and even finding a preschool program for her to transition into. Tracie doesn't like the word "normal." "What is normal?" Rather they want Hailey "to be on a path to living like other children her age,"...one day at a time.

Andee and Emma

Two years ago, Alexandra (Andee) and Emma Barwin, were born three months early on February 12, 2006. They live with their parents, Amber Bonnstetter and David Barwin, in Fort Dodge, Iowa.

Both girls had breathing and feeding difficulties. Andee was 2 pounds 12 ounces at birth and came home after 46 days in the Neonatal Intensive Care Unit at Mercy in Des Moines. Emma, 2 pounds, 11 ounces, had a problem with her epiglottitis. This caused her pain when she ate, and she stopped eating. When the problem was solved, she began eating and was released after 86 days in the hospital. The twins began receiving Early ACCESS services after Emma's release from the hospital. They have received services from the CHSC Birth to Five Clinic, along with services provided by the AEA home teacher and AEA occupational therapist (OT). Their mother, Amber, said "the OT also included a monthly visit to our babysitter, where she was taught many different ways to help the girls and was amazed at some of the things she was shown. " After several months, Andee's motor skills had improved and she no longer receives OT services. Emma, however, was farther behind and her OT services increased. A year after Early ACCESS services began, Emma too, had reached her OT goal and no longer receives OT services. After encouraging the family to have the girls' hearing tested at the AEA, it was discovered that Andee was experiencing a hearing loss, due to ongoing ear infections. She was referred to an Ear, Nose & Throat specialist and subsequently had tubes placed in both ears. Amber indicated that Andee was talking noticeably more just a few days after her myringotomy. At a recent visit to CHSC, both girls were referred to the CHSC nutritionist. Emma, in particular, still struggles with some feeding issues. While they continue to receive Early ACCESS services, the services have changed according to their needs and they have and are making great strides! Amber affirmed, "David and I really appreciate getting the advice and skills to aide our children as we try to give them every advantage possible at having little or no effects as a result of such preterm births."



Amara

Following is a note of appreciation from Mrs. Amanda Schroeder:



"First, let me introduce you to my family. My name is Amanda Schroeder, my husband is Andy & our now 17 month old daughter, is Amara. Amara was born August 16, 2006 with Down's Syndrome and a complete AV canal heart defect for which she had open heart surgery when she was 4 months old. Amara also has many feeding issues. As with any journey, we have hit some bumps as we travel Amara's journey of life, but I also know she's in great hands.

It truly amazes me how our miracle baby has flourished, but when we step back and observe it's very simple. On this Earth we have all sorts of angels that have been put in place for a reason. Our family has been so lucky to have wonderful doctors and nurses and each day it seems a

few more angels appear like Child Health Specialty Clinics' Jody Kealey, Registered Dietitian. Jody has been a blessing to us and has been available to us in many ways. She has come to our house to give us helpful information and tips on how to help Amara with her feeding issues. Jody is also always there for us whether it is by a visit, a phone call, or email when we have questions about Amara's nutritional needs. Because of the help of all her Earth Angels, and her wonderful family and friends Amara is thriving. What a lucky girl we have!

We are so grateful there are angels available that are able to come into our home to assist us in Amara's care. With Amara's health issues, taking her out of the home could even expose her to different challenges. Thank you."